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ABSTRACT

This report presents preliminary findings concerning early intervention services, based on data from in-depth interviews with 75 families with infants, toddlers, or preschool children receiving early intervention special services. Additional data included reviews of Individualized Family Service Plans and Individualized Education Programs, questionnaire data, and documentation of services provided. Families appeared to overwhelmingly choose child-oriented over family-oriented services, and professionals appeared to provide primarily child-oriented services. Possible explanations for these results appeared to be that families see the child's disability or risk status as the reason for receiving early intervention, that families' boundaries imply that larger issues are the family's own business, and that families suppress their own needs and focus on the child with immediate and dramatic needs. Parents also suggested that professionals often desire to keep the agenda on the child. A model is proposed which sees the interrelationship between the family's priorities and the professional's focus as determining the service focus. Results are discussed in terms of legislative requirements for a greater family focus in service provision. (Contains 14 references.) (DB)

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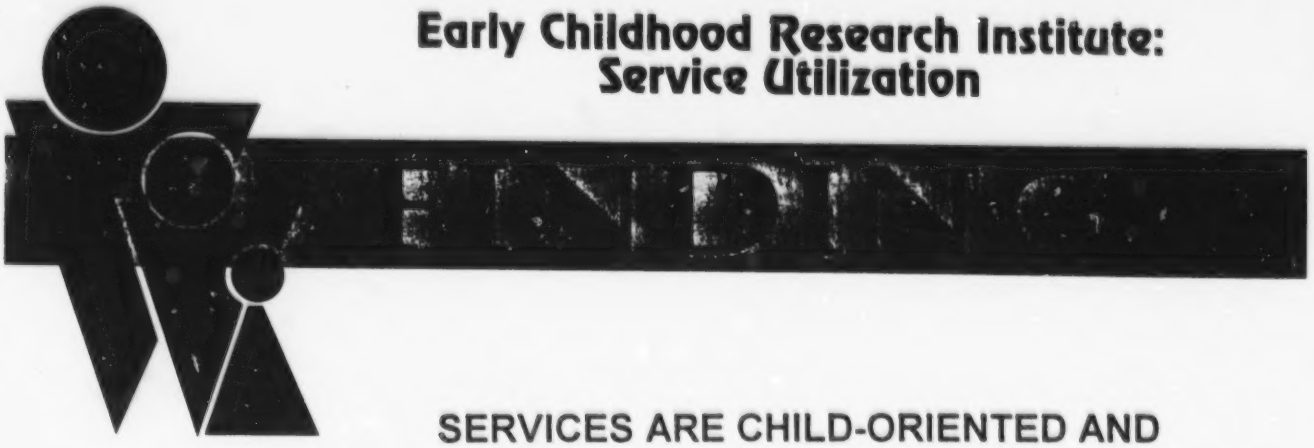


SERVICES ARE CHILD-ORIENTED AND FAMILIES LIKE IT THAT WAY–BUT WHY?

R. A. McWilliam, Lynn Tocci, & Gloria Harbin

August 1995

The focus of services for infants, toddlers, and preschoolers and their families is on the child. Of primary interest is the development and, when appropriate, the health of the child, which is reflected in families' descriptions of assessment, intervention planning, and day-to-day services (home visits, therapy, classroom programs, etc.). The extent of child orientation revealed in our data might not entirely reflect the implied intent of P.L. 99-457 (at least, Part H) and recommended practices in the field (DEC Task Force on Recommended Practices, 1993).

The Part H regulations for the IFSP (SEC. 677) call for a statement of the family's needs, resources, and concerns; a statement of the major outcomes expected for the family as well as the child; and a statement of the specific services to meet the family's and the child's needs. Experts interpreted the law to mean that families should be strengthened (Dokecki & Heflinger, 1989), experiences for parents should be normalized (Bailey & McWilliam, 1991; Ziegler, 1989), and professionals should be trained to provide family services (Bailey, 1989). Recommended practices in early intervention reflect or are compatible with family-centered practices, which Odom and McLean (1993) defined as

> concerned about the welfare of the family and the welfare of the child rather than focusing exclusively on the child. The family (inclusive of the child) becomes the center of intervention decisions and efforts. The intervention program is peripheral to the family, facilitating the family's objectives and priorities for the child. (p. 2)

It seems quite clear, then, that early intervention service providers should attempt to find out about families' concerns that affect even indirectly (a) their capacity to meet their goals for their children, (b) the development of the child, and (c) their abilities to make decisions.

The finding, described in the title, is both expected and important. We have decided to release it before finishing all analyses because further analysis is not likely to change the finding, only to help us understand it better.

METHOD

Data leading to this short report come from 75 case studies divided among nine communities: three in Colorado, three in North Carolina, and three in Pennsylvania. Three fourths of the families have children in Part H (infant, toddler, and family) services, and one fourth have children in Section 619 (preschool) services. The primary data source for this report was in-depth live interviews with families. Other data collected by the Early Childhood Research Institute on Service Utilization include reviews of IFSPs and IEPs, questionnaire data, and documentation of services provided. This report reflects preliminary observations from the data, not the results of completed qualitative or statistical analyses.

The finding reported here stems from interpretations of the whole interview but certain lines of questioning provided much of the information for this early analysis. We asked families questions like,

- "Of all the things you have to think about, what worries you the most? What keeps you awake at night, worrying?"

- "Have you ever talked about this to your service provider?"
- (If no,) "Why not?"
- (If yes,) "How did she respond?"

All interview transcripts have been read and coded; in addition, we reread the transcripts to ascertain the extent to which our main finding held across families. Transcripts were examined to determine whether services were predominantly child- versus family-oriented and whether the family reported wanting child- versus family-oriented services.

FINDING

The finding has two parts: (a) services are primarily child-focused, and (b) families report that they expect this focus to be a child focus. Many say that family-level concerns are their own business, and they don't expect early interventionists to be involved in non-child-related issues.

The table below shows the frequencies of child- versus family-oriented services cross-referenced with families' desires for the orientation of services.

	Child-Oriented Services	Family-Oriented Services
Family Wants Child-Oriented Services	65	0
Family Wants Family-Oriented Services	3	7

Among families who receive predominantly child-oriented services, some experience a certain level of attention to family issues but not enough to consider the services *family-oriented*. We are currently developing a rating scale to measure the extent of family-centered practices as revealed by the interviews. Recognizing that orientation to family-systems and -level concerns is but one aspect of family-*centeredness*, we plan to include items that will provide more complete data on family-*oriented* services.

To some extent, family-centered services focus on child needs if that's what the family says they want. But solely responding to what families want implies a unidimensional definition of family-centeredness: making families happy. Case study data and previous research suggest that principles and policies of family-centeredness have four dimensions:

- responding to family priorities,
- empowering family members,
- taking a holistic approach to the family, and
- being insightful and sensitive to families (Bailey, 1987; Barber, Turnbull, Behr, & Kerns, 1988; Dunst, Johanson, Trivette, & Hamby, 1991).

Services appear to be family-centered on the first dimension, probably not on the second, not on the third, and therefore probably not on the fourth.

DISCUSSION

In light of the intent of the law, research on the importance of family support, and recommended practice, how or why do families have this almost exclusively child orientation? Our interview data suggest that answers to this question lie within both families and professionals, as follows.

POSSIBLE FAMILY EXPLANATIONS

- The reason for receiving early intervention is the *child's* disability or risk status. Sample statements:

I knew my daughter needed some kind of therapy. She needed to be into something.

We were hesitant. They more or less pushed it down there that they really thought it would be something helpful for him and... then after they got like discussing it more and telling us how it would be for him and stuff like.... I think it was all right with us if it could help him.

- Families' boundaries are such that some things are their own business (i.e., they don't know the professional well enough to disclose other business). Sample statements:

I don't tell her things like, "Hey, I didn't sleep last night. I really have things bothering me like my money," because that's my business.

I'd be shocked if she asked. I don't feel like she's a total stranger; it's just that those types of problems are my problems. She's the therapist; she's here to work with [my child]. She's here to help my son.

- Parents suppress their own needs and focus on the family member with immediate and dramatic needs. Sample statements:

[My needs] are second ... he's first. He's first in our life.

So it's mainly him, which that's what they're here for. That's what they're really here for–him....

POSSIBLE PROFESSIONAL EXPLANATIONS GIVEN BY PARENTS

- Professionals overtly or covertly set and sometimes keep the agenda on the child. Sample statements:

Quotation from interviewer's field notes: *The way Mom described it is she brings [her child] in, hands her to the PT, who does stretching exercises. When session is over, the PT hands the child to the mom and says, "I'll see you next week," and they leave.*

I think they should tell the parents, "We are here if you need us. If there is a life change please come to us," so the mother isn't sitting back and thinking, "Gee, should I tell them?"

I figure that if I want to know more, I just got to pry it out of her [service provider] again. It just felt like I'm on this island by myself and I have to take this rowboat and row it across to get some information.... Nobody really called and said we're doing an assessment on your child, would you like to come, because I would have come.

Other professional-centered possibilities are that (a) professionals feel they do not have enough time to spend on family-level assessment and intervention; (b) some professionals might be overwhelmed at the expanded role inherent with a holistic, family empowerment approach; or (c) many professionals might have a limited understanding of family-centered approaches, focusing on eliciting and respecting families' child-level priorities but not on promoting families' capacities for independence, eliciting their family-level needs, or anticipating their unspoken concerns.

Family explanations for families' having a child orientation emanate from their experience and values. A family would not be involved in early intervention if their child did not have disabilities or was not at risk for disabilities. Not surprisingly, families expect the focus to be on the child. They are not as likely as professionals to have been exposed to a family-systems approach to early intervention. Families' maintaining boundaries between what is private and what is disclosed to professionals is a normal act of family functioning. The permeability of boundaries can be expected to differ between families and to depend on the characteristics of the service provider, other things going on in the family's life, and the length of the relationship (Porter et al., 1995). Finally, families' devoting the most attention on the member with the most significant needs is consistent with the cultures most heavily represented (Euro-American, African American, Native American). Many families are surprised that there is even an option. "Of course we focus on the child!"

Families' priorities are influenced by their service providers' values and behaviors; research is needed, however, on the extent to which professionals initiate and reinforce a child-centered approach to early intervention. Most families indicate that professionals are responsive; they say they give families choices, schedule activities at families' convenience, and respect families' intervention priorities. What they do not say, however, is that service providers work actively with the parents and other family members to support the family ecology. We found many families who have not told their service provider about the things that bother them the most–the things that keep them awake at night. Why not? Families say they should be able to handle those kinds of things themselves. Such responses raise questions about the extent to which early intervention professionals have adopted a family focus.

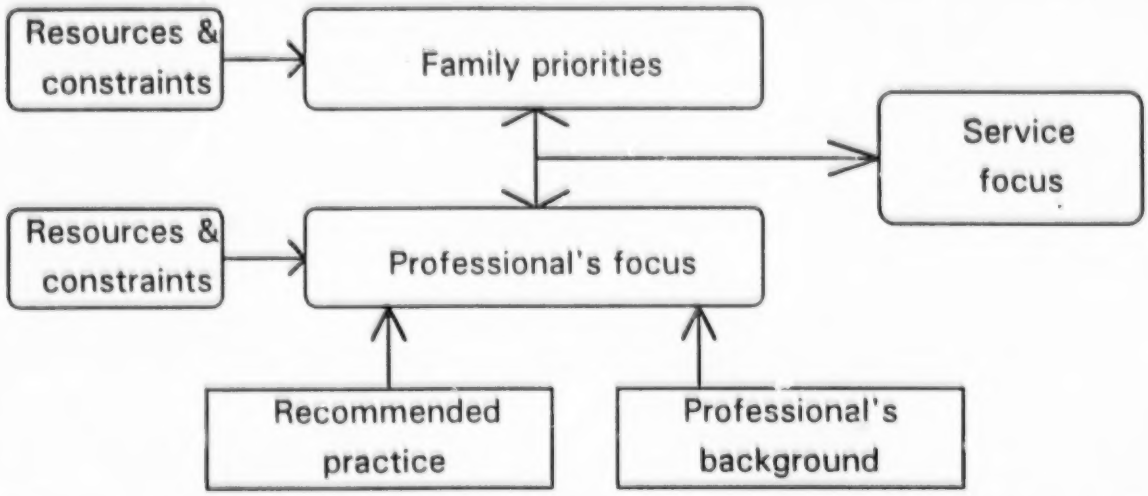
Our research has led us to hypothesize a model, shown in the figure on page 4, explaining the predominantly child focus in service delivery. The focus is the result of family priorities and the professional's focus, both of which influence each other. Families who concentrate on child issues are likely to encourage such a focus in service providers, especially if that's the most familiar focal point for professionals. Similarly, professionals who begin interactions with families by assessing the child and then move on to child intervention planning and finding services for the child are likely to encourage such a focus in families. Our data suggest that recommended practice and the professional's background also contribute to the

professional's focus. Interviews with both families and the service providers who work with them reveal that professionals are reported to be fulfilling many of the functions recommended for the field (DEC Task Force on Recommended Practices, 1993). Background influences include training and professional acculturation. Most early interventionists are trained almost exclusively to work with children. Special education and therapy training (e.g., occupational therapy, physical therapy, speech-language pathology) includes very little attention to working with families (Bailey, Palsha, & Huntington, 1990; Bailey, Simeonsson, Yoder, & Huntington, 1990).

Other preliminary data from the Early Childhood Research Institute on Service Utilization corroborate our findings. For example, (a) the IFSPs and IEPs of families in the case studies show that most goals are related to child development, health, and behavior (Gallagher, in prep.); (b) professionals' ratings of the importance of family control are higher than families' ratings (Kochanek & Buka, 1995); and (c) interviews with administrators confirm that professionals are responsive but don't necessarily work to support the family ecology (Harbin, Rooney, & Ringwalt, 1995). Interviews with administrators also revealed that they perceived service providers to be somewhat uncomfortable asking families "personal" questions (Harbin et al., 1995). In one community, however, comfort with getting to know the family on a personal level is considered imperative, so they attempt to hire professionals with that attribute. Thus, we are quite confident in our finding that, with the possible exception of this community, services are primarily child-focused and that families are comfortable with this focus, *given their experiences in early intervention.*

Other studies have found similar indicators of a strong child focus. In two studies evaluating Part H services in North Carolina, intervention was concentrated on child issues, even though professionals had and reflected family-responsive beliefs, and IFSPs were highly child-oriented (McWilliam, Ferguson, et al., 1995; McWilliam, Harbin, et al., 1995). Similarly, in a study in Iowa, home interventionists were observed to spend the greatest percentage of time interacting directly with the child with a disability and to focus their interactions with the family on the child's skill development or caretaking needs (McBride & Peterson, 1994). Our model theorizes that professional characteristics and behaviors, as well as family priorities, should be explored to discover the extent and reasons for a strong child focus and relatively weak family focus in early intervention.

Does our finding then mean that the legislative intent and assumptions about the importance of family-centered practices are incorrect? Absolutely not. The pervasiveness of a focus on the child suggests that (a) family-centered practices are more complex than current practice tends to reflect (i.e., there's more to family-centered practices than training parents to be effective teachers of their



Model Hypothesizing Reasons for a Strong Child Focus and Weak Family Focus in Early Intervention

young children), (b) family satisfaction with a child focus is natural, and (c) professionals tend to keep the focus on the child. Should professionals focus on the family when the family expresses satisfaction with a child focus? The responsivity component of the family-centered approach would say that professionals should do what families want. If, however, they have not *opened the door* to a fully family-centered approach, then families' satisfaction with or expectation of a child focus could be the perspective of an "uninformed consumer." An interview study of 20 families and 20 service providers in North Carolina led to this conclusion (McWilliam, Harbin, et al., 1995). Until we are sure that service providers are implementing all four components of family-centered services, as defined here, we cannot be sure that families would see the benefit of a family-centered approach. Therefore, the validity of the legislative intent and recommended practices hinges on, first, enough service providers understanding the full concept of the family-centered approach and, second, families having enough exposure to this approach to respond as informed consumers.

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